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Improving equality of access to Independent Mental Health Advocacy (IMHA): a report for providers



This report aims to help Independent Mental Health Advocate (IMHA) services reach everyone who is entitled to their support. Our intention is to assist IMHA providers to achieve the best possible outcomes for all people treated under the Mental Health Act 1983 amended in 2007.

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Introduction

This report aims to help Independent Mental Health Advocate (IMHA) services reach everyone who is entitled to their support. Our intention is to assist IMHA providers to achieve the best possible outcomes for all people treated under the Mental Health Act 1983 amended in 2007. Drawing directly on the findings and recommendations of the national review of the quality of IMHA services in England (Newbigging et al, 2012), this report highlights the problem of unequal uptake of IMHA by some groups of 'qualifying patients' and explores what can be done to change this situation. We draw attention to the obligations of IMHA services under the Equality Act (2010) and provide concrete suggestions about how to take effective action and improve practice when working with people sharing relevant protected characteristics. (Equality and Human Rights Commission, 2010a)

In this report, we suggest some steps that IMHA providers can take to help them identify, understand, and address the barriers to the full and effective use of their service by everyone who is entitled to access it. In summary these are:

- Understanding the needs of the local population is key to developing an equitable IMHA service
- Equality monitoring and evaluation are central to delivering accessible IMHA services.
- Working together with existing specialised community organisations is an effective way to meeting diverse needs
- IMHA services must make themselves visible and accessible to everyone who has the right to use the service
- IMHA providers must do everything possible to enable effective communication with qualifying patients
- Advocates need to build trusting relationships with service users.

Background

'It took me ages to realise that I could actually do something about things instead of just having stuff done to me.'

(Beresford, 2013)

As many service users have reported, undergoing compulsory psychiatric treatment is a major event which has serious effects on a person's life. It can be confusing, overwhelming and disempowering. Having someone on your side during this difficult and distressing experience can be very helpful. An IMHA can ensure that the service user's opinion on all matters affecting them is heard, understood and considered. IMHA services are available to most people who are detained in hospital or subject to community treatment orders (CTOs). However, as research on IMHA practices shows, there are many other issues that influence whether IMHAs actually reach everyone eligible and build trusting and helpful advocacy partnerships. (Newbigging et al, 2012) This briefing discusses specific barriers and difficulties that prevent some groups of service users from accessing IMHA even though they qualify for this support. It is important for IMHA providers to recognise these barriers and understand how they operate, and how they can be removed so that everyone who is eligible for IMHA has access.

People who are eligible to use IMHA services in England are:

- people detained under the Mental Health Act 1983 amended in 2007 (even if on leave of absence from the hospital), but excluding people who are detained under certain short term sections (4, 5, 135, and 136)
- conditionally discharged restricted patients
- people subject to guardianship
- people subject to supervised community treatment orders (CTOs).

Other patients, who are informal, are eligible for IMHA services if they are being considered for section 57 or section 58A treatment (i.e. treatments requiring consent and a second opinion). This includes people under the age of 18 who are being considered for electroconvulsive therapy (ECT).

Unequal uptake of IMHA – research findings

The right to be heard (2012), a two-year research study looking at the quality of IMHA services, involved consultation with 289 different stakeholders in group or individual interviews including 90 people eligible for IMHA. Across the different areas in the study, the research found that IMHA was only used by between 20 and 55 per cent of the number of qualifying patients who were entitled to access statutory advocacy support (Newbigging et al, 2012). The researchers also considered some of the circumstances contributing to this situation and identified seven groups of qualifying patients who remain particularly underserved by IMHA. They include:

- people from black, Asian and minority ethnic (BAME) communities
- people with learning difficulties
- older people with dementia
- people who have hearing impairments or are D/deaf
- young people
- people placed out of their area of residence
- people on CTOs.

People from these groups have much lower uptake of IMHA. Many participants in this study expressed concern that people from these groups are also likely to be the ones who most need this service. The reasons why they did not access IMHA included not understanding its purpose and how it can be helpful. In addition, some qualifying patients did not even know that the service existed.

This briefing considers how equality issues affecting people from these groups get in the way of accessing effective IMHA support. This is not meant to imply the similarity of these groups, nor of the people in them. Addressing each and every individual situation and working in a person-centred manner remain central tasks for advocates. However, to provide a good quality service, it is essential to have a sound understanding of the specific issues faced by different groups. Working in an inclusive way means being able to see the bigger picture and consider the broader circumstances of service users' lives beyond their patient role.

'I just keep myself to myself and stay in my room a lot because I am the only Black female patient here.'

Non-IMHA user (Acute ward) (Newbigging et al, 2012)

The right to be heard (Newbigging et al, 2012) revealed the failure of many IMHA providers as well as commissioners, to take steps to understand the make-up of the local populations they serve. This is a step that is essential to developing and delivering an equal and inclusive service. There has been a general increase in the use of both detention in hospital and CTOs. (Health and Social Care Information Centre, 2014, pp. 10, 11, 22) Several reports have demonstrated that these measures are imposed more frequently on members of BAME communities (Centre for Social Justice 2011, Care Quality Commission 2010, Healthcare Commission 2008). The evidence from these reports and recent mental health policy (HM Government 2011) clearly calls out for an

equality analysis of IMHA provision to ensure that no one is deprived of IMHA access. Furthermore, most organisations do not collect and monitor equality data in sufficient detail to understand who is accessing IMHA and identify potential gaps. This kind of a comparison requires specific information about, for example, age, ethnicity, sexual orientation and impairment. This curtails the development of IMHA which serves different groups equally and effectively meets their specific needs.

Duties of IMHA services under the Equality Act 2010

As a service with a public function, IMHA is subject to a general duty under the Equality Act, 2010. This includes the duty to ‘advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it.’ (Equality and Human Rights Commission, 2010b) The characteristics protected by the Act are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. It is clear that the groups of service users which make low or no use of IMHA share some of these protected characteristics.

Other provisions of particular relevance to IMHA providers are the general duty ‘to take steps to meet different needs’ (Equality and Human Rights Commission, 2010b) and the specific duty to publish information showing how they have met this. This information is also known as ‘equality data’. To be able to publish this information, an IMHA service must first specify the equality objectives that it wants to achieve. It is also required to keep records of all relevant data to enable the monitoring of its progress in achieving those goals.

In addition to reinforcing these statutory obligations it is important to emphasise the need for an underlying equality-promoting awareness and philosophy behind IMHA. Providers should question their approach to all the different groups they serve and commit to securing a fair and equal distribution of their service. The Equality Act can be used to kick-start and advance this goal. IMHA providers can apply some of the Act’s provisions directly to achieve changes in service delivery. These include the recognition that:

- ‘bodies subject to the duty should also be aware of the diversity of experience within any one group of people’
- ‘equality does not mean always treating everybody the same way’ and
- ‘in some circumstances compliance with the general equality duty may involve treating some persons more favorably than others’ (Equality and Human Rights Commission, 2010b).

An equitable IMHA service must provide reasonable accommodation, as defined in the United Nations Convention of the Rights of People with Disabilities (ratified by the UK in 2009). Like any other public service, it is obliged to make ‘necessary and appropriate modification and adjustments ... to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.’ (United Nations Convention on the Rights of People with Disabilities, Article 2)

Suggested principles for IMHA provision

This section suggests some steps that IMHA providers can take to help them identify, understand, and address the barriers to the full and effective use of their service by everyone who is entitled to access it. Drawing on *The Right to be Heard* and several other reports that explore equality in a mental health context (Faulkner 2014, Beresford 2013, Kalathil 2011), this briefing also proposes some potential ways to break down these barriers and illustrates these with practice examples. The following list of key issues should not be read as definitive, nor is it meant to guarantee any quick and easy solutions. Central to the process of ensuring equalities in IMHA provision is an ongoing commitment and openness to rethinking and advancing practice.

Understanding the needs of the local population is key to developing an equitable IMHA service.

‘There is no better way of finding out how to involve previously excluded groups than going out and asking them directly.’ (Beresford, 2013)

To develop a targeted and effective service, IMHA providers must understand the needs of the local population and especially the demographic profile of people being treated under the Mental Health Act. This means first becoming aware of the different groups of service users in the local population who are likely to need IMHA. Second, this process involves learning about the specific requirements of these groups based on characteristics such as ethnicity, age, gender, sexual orientation and impairment. The required knowledge goes beyond basic access requirements such as the need for language interpreters, and needs to include a broader understanding of culture, social background and history.

‘Coming from a cultural background that does not believe in talking to strangers about personal matters, hospital sectioning was the stuff of nightmares.’ (Faulkner, 2014)

Opening up IMHA to diverse communities is also about an organisation adopting equality principles in all it does. The input of those whom IMHA is supposed to serve will be indispensable in the process of developing these principles and ultimately, a good quality advocacy service.

‘We need to find out from service users proactively why they aren’t getting involved and what would work to change that.’ (Beresford, 2013)

Equality monitoring and evaluation are central to delivering accessible IMHA services.

To enable the monitoring of differences in IMHA uptake and assessment of improvement, it is important that the equality data of people who use these services is consistently and routinely recorded. The data recorded should extend beyond age and gender characteristics and include information about ethnicity, area of residence, sexual

orientation, and impairment. The first step is to document and analyse the proportion of IMHA support given to service users who are likely to experience multiple discrimination.

As a second step, a comprehensive evaluation of IMHA provision is needed that goes beyond statistics and questions the adequacy and efficiency of the support given to people from these groups. Service users with experience of compulsion must be meaningfully involved in any such evaluation, including assessment of their satisfaction with IMHA and its effectiveness in meeting their aspirations. We particularly recommend consultation with service users who experience multiple forms of discrimination.

Working together with existing specialised community organisations is an effective way to meeting diverse needs.

'It's horses for courses. As a black mental health service user group we could offer the kind of advocacy that other BME service users would trust and value.' (Beresford, 2013)

IMHA services need to find out which organisations are already offering support and advocacy to particular groups in their area and get to know them. They should work out the best ways to learn from these organisations how to make IMHA services accessible to different groups and find ways to work collaboratively to meet people's needs.

Practice example

Securing specialist skills to meet diverse needs

VoiceAbility has provided an IMHA service across a hospital in Northamptonshire. There is a specialist unit for D/deaf service users. VoiceAbility worked with the hospital managers to identify the best way to deliver an effective IMHA service: concerns existed that service users were not accessing the service provided by hearing advocates working alongside translators.

The IMHA service recognised that it needed to offer something different: a service that was responsive to people's needs and understood Deaf culture. It initially sub-contracted with a specialist provider who provided deaf IMHAs. Whilst this resulted in a positive uptake of the service, there were some difficulties which impacted on the continuity of the service and VoiceAbility found it hard to provide managerial support to an external agency which had different recording systems. This led to VoiceAbility directly employing a deaf IMHA who provided dedicated support to the ward but would be part of the larger team.

'Once we had a deaf advocate going onto the ward we saw service users gaining confidence in approaching the advocate. In the past it was very easy to say "no thanks we don't need any support". Once they saw a deaf advocate from the deaf community they could relate much easier. Put simply, employing someone who used BSL as their first language made the service much more accessible to deaf patients'.

Practice example

The move to cut bed numbers in psychiatric hospitals means many young people are likely to be detained out of their area of residence. This makes it even more urgent that they are guaranteed support when putting forward their views and their needs. The Young Minds website features a video where young people themselves talk to their peers about their right to be heard. The same website includes a personal story of one young person's experience of IMHA, as well as a comprehensive and accessible explanation of what IMHA is. The MAZE Advocacy website set up by Advocacy in Somerset, provides online tools designed by young people to help get young people's point of view across, and ensure other people hear and understand what young people with mental health problems have to say.

<http://mazedadvocacy.net/>

Practice example

IMHA providers' ability to engage with community groups is likely to be strengthened if their own organisational practices and principles are inclusive and they are proactive about equality, diversity and human rights. This may include; having equal opportunity recruitment practices, developing a governing body that reflects the diversity of the local area, reporting annually about progress around diversity and equality issues, using equality impact assessments, and being positive about employing mental health service users and disabled people.

IMHA services must make themselves visible and accessible to everyone who has the right to use the service.

'The rule of thumb should always be that the organisation or individual seeking to involve people should take responsibility to overcome people's fears and uncertainties about it, rather than just expecting them to turn up.' (Beresford, 2013)

IMHA providers need to make sure that each and every service user who is entitled to use their service knows about it and understands what it offers. This is essential so that each individual can make a free and informed choice about whether or not to use IMHA.

'We have to be actively working to involve people. People who aren't involved are not going to come knocking on your door saying 'Let me in! Let me in!'' (Beresford, 2013)

'They are not 'hard to reach', they are just more of a challenge. That is why we need properly trained outreach workers to go and talk with these people. (Beresford, 2013)

Given the personal circumstances of people experiencing compulsory measures, the information about IMHA needs to be very easy to understand and in appropriate formats. Advocates must make their work visible both on wards and inside community services, making it clear at the same time that they do not belong to, and are

independent of clinical teams. Informative material about IMHA should assume that people will know nothing about the service. It is important that such material is inclusive and explicitly welcomes diverse groups of potential IMHA users, acknowledging their ethnicity, age, sexual identity, impairment or disability.

These stepped-up efforts to reach everyone are likely to result in a higher uptake of IMHA and may therefore raise issues about the capacity of IMHA providers to meet demand. Committing to opening IMHA up so that it is accessible to all qualifying patients has the potential to substantially change provision, which will require strategic planning and negotiation with local commissioners.

IMHA providers must do everything possible to enable effective communication with qualifying patients.

Being able to understand one another is the basic precondition for any effective communication. An interpretation service for qualifying patients whose first language isn't English or who use sign language should therefore be organised. People with learning difficulties may also need support with communication. However, it must be remembered that the goal of advocacy is not only to ensure that service users understand their situation and their rights. Importantly, it is also about enabling them to fully express their needs and concerns in the way that is most familiar and natural to them. For this reason, improving equalities within IMHA provision cannot be reduced to the issue of language accessibility. An equitable service should use the communication styles and formats which are easiest and best for specific groups of local service users.

Most importantly, however, good communication skills include careful listening, paying attention to things that are not said, being as non-judgmental and prejudice-free as possible and engaging and empathising with the other person:

'It's the conversation, the talking without being judged, without any bias. Because you're talking to somebody who doesn't know anything about you. You're telling them about you, they don't already know you. So you give it to them and they give you back the support that you need.' (Faulkner, 2014)

Advocates need to build trusting relationships with service users.

Gaining the trust of service users is not a matter of using difficult technical skills. The advocate's identity, their sensitivity and knowledge of specific groups all play a crucial role in that process. Their ability to empathise and build rapport are also paramount:

'It's about what you don't have to say or explain.'
(Faulkner, 2014)

'[In hospital] I felt like I was being punished, I felt like I was on remand rather than in hospital, and it was nice that I had an advocate because I felt like it was the only voice I had apart from my own...' (Newbigging, 2013)

IMHA providers need to consider how to offer advocacy partners a choice about their advocate's gender, age, ethnicity and other specific characteristics. This means paying attention to the diversity of IMHA teams as much as this is feasible given their overall size. It is important, however, that services always begin by asking individual service users about their needs. It is not good practice to assume people will want an advocate of their own gender, ethnicity, age group or cultural background.

'The reason people have been nasty towards me was because of my race... So I think I would have needed a counsellor who would have understood that. Even if that person was white, if they would have understood that...' (Kalathil, 2011)

'They didn't put anything in place in relation to my sexuality, what experiences I'd had in relation to that, how I felt rejected by my family. Nothing to offer me at all. The staff were not understanding. I had nothing in terms of support around sexuality, support groups. I had nobody for a long long time.' (Transgender woman) (Faulkner, 2014)

It is sometimes helpful to focus advocacy on one particular group of service users, but doing this is not in itself a guarantee that trust will be gained. The importance of provision from advocates who understand is illustrated in the following practice examples of specialised IMHA services:

Practice example

Founded in 1989, Leeds Advocacy has considerable experience in providing advocacy for people with learning difficulties in order to prevent their marginalisation and help them speak for themselves. Advocates use graphic communication or take time to find out about the person's preferred way of communicating. This helps them to better understand people who don't always give clear instructions and sometimes don't communicate verbally. The long-term expertise of this organisation is central to safeguarding the rights and enhancing the choices of people with learning difficulties who are detained or restricted under a Mental Health Act section.

Conclusion

Ensuring equality of access within IMHA services means reaching all qualifying patients regardless of their ethnicity, age, gender, disability, beliefs, sexual orientation or any other characteristics protected by the 2010 Equalities Act. It also means taking these characteristics into careful account and developing a service that can understand their impact and meet people's needs.

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